

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN6379001

Exhibits: Nil

Dated:

## INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 October 2021.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1951 and my address is known to the Inquiry. I have been married to my husband GRO-B since GRO-B. We have been together for GRO-B years. We lived in GRO-B for 10 years before moving to GRO-B in 1985. My first job was in GRO-B then worked in GRO-B for GRO-B GRO-B County Council until 1981 when I had my first son. After my second son was born in 1984, I began doing housework for various clients. I now work for one person on a Monday morning which I enjoy.
2. I intend to speak about my infection with Hepatitis C (HCV) contracted from blood transfusions received in 1981 and 1984 following the births of my two sons. In particular, I intend to discuss the nature of my

illness, how the illness affected me, the treatment received and the impact it had on myself, my family and our lives together.

## **Section 2. How Infected**

3. My first son was born in 1981 at Eastbourne Hospital. I was given a D&C, during the course of which I haemorrhaged. I remember the doctor coming around and saying that he thought they were going to lose me. I was then hooked up to a blood transfusion. I was very unwell and couldn't hold my son for three days. When my second son was born in 1984, I was also given a blood transfusion. The risks involved were not explained on either occasion. My health was fine afterwards; I didn't feel any different.
4. On 3 July 2013, I began to feel very unwell. I was lethargic and unable to cope with daily life. It felt as if my life was draining from my body. I didn't know what was causing me to feel so unwell. I just knew that I couldn't keep going any longer. I went to my GP, Dr GRO-B at the GRO-B surgery in GRO-B. She was extremely nice and offered to do an MOT blood test. The results revealed a problem with my liver. However, she was not initially able to identify the cause of the damage.
5. I continued to go for various blood tests so that my GP could try to locate the problem. In October that year, she arranged for a scan at the hospital. Unfortunately, the scan did not shed any light on the cause of my ill health. Dr GRO-B was confused. I continued to receive blood tests. During one appointment, she looked through a medical encyclopaedia to work out what was damaging my liver. That is when she spotted Hepatitis C and arranged for a test.
6. In December 2013, Dr GRO-B diagnosed me with Hepatitis C. I had no idea what the nature of HCV was at the time. It seemed as if Dr GRO-B didn't quite understand herself. She asked whether I consumed a lot of alcohol or used drugs. However, she took one look at me and assured

## ANONYMOUS

me that she was quite sure this was not the case. Initially, she seemed at a loss as to how to help me, nor how I could have contracted the virus. She did not mention the possibility that I could have been infected from either of the blood transfusions received after my sons were born. I was referred to a specialist at GRO-B Hospital.

7. In March 2014, I saw the specialist, almost a year after my initial diagnosis. It was stressful to be left in the dark for so long as to where I could have contracted the infection or my prognosis moving forward. The specialist confirmed my diagnosis and asked whether I took drugs or consumed a lot of alcohol. When I said that I did not, he asked whether I had received any blood transfusions. Up until this point, I didn't know there was a connection. He explained that there had been problems with contaminated blood and that this was the likely source.
8. I was very confused when I was informed that the source of my infection would have been one or both of the transfusions I received in 1981 and 1984. I couldn't fathom how it was not until 2013 that the virus manifested and had a noticeable effect on my health. The nurses explained that the virus affects patients differently. Whilst some will notice an effect immediately, for others it will plateau for years and years before suddenly attacking the body.
9. I was then referred to the Royal Sussex County Hospital for a fibro scan which I underwent in July 2014. It was confirmed that my infection was caused by the transfusions I was given in 1981 and 1984. The Royal Sussex were very good. GRO-B has always accompanied me to appointments and was able to explain anything I didn't understand. It was explained that I had fibrosis which, if left untreated, would develop to cirrhosis and then cancer. This was very worrying. They also discussed initiating me on a year-long course of treatment.
10. It was recommended that my husband and two sons be tested. I was very upset at the intimation that I could have transmitted the virus to my family. I was quite sharp with the consultant as I was confused as to

how Hepatitis C could be transmitted. However, he was still quite kind. GRO-B has since been tested, the results of which were fortunately negative. My younger son is also all clear. Our eldest son has refused to have a blood test. That is his choice. He doesn't believe he is at risk as I was given the transfusion after his birth.

11. The Royal Sussex kept waiting and delaying the treatment because a new treatment from America was awaiting approval from NICE. They warned me that the treatment that was presently available was much like a chemotherapy and would entail difficult side effects GRO-B and I were concerned. We told nobody except our two sons. I was also very worried because I visited my mother in her care home every week. I was afraid of going on this medication and being poorly. I didn't want her to be aware of any problems.
12. Nevertheless, the Hepatitis C nurses were very nice and supportive. They really helped us through it. I do not have a bad word to say about them. They continued to wait for developments in the new treatment. We were all hanging on and waiting for this. However, when the treatment was approved, it was only eligible to those with cirrhosis. As I only had fibrosis, I did not qualify. It was bitter-sweet; whilst I was grateful not to be in a worse physical health, I was excluded from the new treatment unless my condition deteriorated further.
13. On 16 June 2015, I had another fibro scan. Afterwards, the hepatitis nurse revealed that she had some bad news; my liver had got decidedly worse and I now had cirrhosis. She added that the good news was that I now qualified for the new treatment which was three months long rather than a full year. I was frightened and bewildered as to how the fibrosis had suddenly and rapidly deteriorated to cirrhosis. The nurse explained that is how the virus works. It was pretty scary.

**Section 3. Other Infections**

14. I have also been tested for HIV. I feel very thankful and fortunate that the result was negative and that I only contracted HCV.

**Section 4. Consent**

15. I was always fully informed about the tests that I received for Hepatitis C.

16. I was requested by the Hepatitis C nurses at the Royal Sussex County Hospital if I would be prepared to partake in some university research. I agreed. The purpose of the research together with how my blood samples would be used, was fully explained to me.

**Section 5. Impact**

17. My diagnosis with HCV has had a significant impact on my mental wellbeing. As a family we tend to keep things to ourselves. I'm not sure this is always beneficial but that's just how it is. GRO-B certainly doesn't want my infection mentioned outside the family. As a result, I have kept a lot of my anguish to myself. I have never felt angry, just very upset and distressed.

18. My diagnosis was not something I felt that I could discuss, not even with my husband. To this day, I do not know if he fully understands my mental anguish I went through at the time of my diagnosis. I tried to be strong but even my GP, Dr. GRO-B noticed my distress. She suggested some antidepressants. However, I refused medication as I have always been one to just get on with things.

19. I am quite close to my brother. When I was feeling particularly low, I just felt that I needed to confide in someone outside my immediate

## ANONYMOUS

family. I knew that he would be supportive. He was quite devastated for me but of course there was nothing that he could do. He would check up on me. Nowadays, he does not mention it unless I speak about it. However, more recently, we have discussed my infection again as he has been following the progress of the Infected Blood Inquiry.

20. On 18 December 2015, I finally began treatment which lasted three months. The Hepatitis C team warned me on potential side effects. However, I was still frightened as to how I was going to feel, particularly as I didn't want my mother to know. However, strangely, just before I began treatment, my mother died. She never knew that I had been infected. This was a relief as she would have been absolutely devastated.

21. As far as I can recall, I didn't experience side effects. However, I didn't feel brilliant. The tablets also thinned my blood. Nevertheless, I was able to continue with everyday life. Other people would never have known that I was undergoing treatment. I was required to have blood tests at GRO-B Hospital every four weeks which were then sent to the Royal Sussex County Hospital.

22. As the weeks progressed, the hepatitis viral load diminished. After three months, the virus was cleared. An undetectable quantity remains. The Royal Sussex were so pleased that the new medication was successful. I now go for an abdominal scan and blood test at GRO-B GRO-B Hospital every six months as I am at an increased risk of cancer. This was upsetting to learn. The results are sent to the Royal Sussex, following which I have a consultation with the nurses. Since the pandemic, this is a phone call instead, which is fine.

23. Since the treatment, I began to feel unwell. I consulted with my GP who ran some blood tests. I was diagnosed with pernicious anaemia which results in a vitamin b12 deficiency. I was given a weekly course of injections which I now receive every 10 weeks. When I asked the Royal

## ANONYMOUS

Sussex if this could be attributed to the HCV or resultant treatment, they were unsure. I have also had a thyroid imbalance for some years. Treatment appeared to unsettle my thyroid and so my medication has to be adjusted accordingly.

24. My diagnosis with Hepatitis C impacted the relationship between GRO-B and I. I got the impression that he was not happy with me. The only known route of transmission at the time was unprotected sex. It wasn't until a year later when we saw the specialist that we realised I must have contracted the virus through contaminated blood. As the virus was associated with drug use and sexual promiscuity, I felt that GRO-B was suspicious as to the route of my infection. This was particularly hurtful and led me to feel completely isolated and alone.

25. As a result of the stigma surrounding the virus, I have kept my diagnosis between my immediate family and my brother. Some years ago, a friend of mine told me about her next-door neighbour who had Hepatitis C. She then added something along the lines of, 'so you know what he's been up to; What sort of life he's led'. This comment has always remained with me. I have led a clean and healthy life and I was upset at the possibility that others would judge me for an infection that I contracted through no fault of my own.

26. On one occasion, I sat in the waiting room of Eastbourne Hospital whilst my aunt had an appointment. A screen flashed with information about HCV. It was a relief to learn that I must have contracted the virus through contaminated blood. However, I was still reluctant to share my diagnosis with others as it was still associated with sexual interaction and drug use. As a result, my illness has remained very much a private family matter. I told my brother at one stage because I was not coping very well. He is also a very private person and so I trusted him.

27. Prior to my diagnosis, I was not overly social. However, I have always been friendly with my neighbours. My diagnosis certainly led me to

## ANONYMOUS

avoid others as I felt very low. Nevertheless, I continued going to work and tried to be happy. It was quite a strain trying to present to the outside world that everything was fine and that I was content when inside I was very much struggling. Wearing that façade took its toll on me, but it was the only way I knew how to manage.

28. My sons were very upset to learn of my infection. However, they coped very well. Initially, I think they were afraid that they were going to lose me. For many months, my prognosis was very up in the air and I did not begin treatment immediately. To this day I do not know how my health will look in the future. My sons regularly ask how I am and they are aware that I am speaking with the inquiry, of which they are very supportive.

29. My dental treatment has not been affected by my HCV status as I did not declare it. When I was undergoing treatment, the dentist would ask if I was receiving any medication. I couldn't face divulging that I was undergoing treatment for Hepatitis C. I was aware of the stigma surrounding the virus and was constantly fearful that I would be denied treatment as a result.

30. I have felt that I have been subject to stigma by staff at GRO-B GRO-B Hospital as a result of my infection. When I attended the Hospital for an abdominal scan, they were muttering something about Hepatitis C. I felt that they were very sharp and hostile with me which was quite traumatic. When I explained that I had cirrhosis of the liver from contaminated blood, they couldn't have been kinder. I think it is reprehensible that I should have to justify my infection and treatment.

31. Every time I go for the blood test, my notes indicate that I am undergoing a Hepatitis C or cirrhosis screening. Doctors know why they are doing the test. If I find that they are being hostile or judgmental, I disclose why I am being tested. I sometimes feel that staff are judging me for appearing not to lead a very respectable life. I don't experience this stigma at the Royal Sussex in Brighton. HIV and HCV



seem to be more prevalent in the Brighton area which is perhaps, why they are more accepting.

#### **Section 6. Treatment/Care/Support**

32. If I recall correctly, following my diagnosis, the staff at the Royal Sussex County Hospital offered me counselling and psychological support. I chose not to take up this offer. Dr **GRO-B** also offered me medication when I was feeling depressed. Whilst I refused, I appreciated that she was very observant to my mental health.

#### **Section 7. Financial Assistance**

33. In March 2015, I applied to the Skipton Fund. I filled in what I could. Then I took my application to the hepatitis nurses who completed the forms and sent them off. They were very kind and helpful. My application was initially returned to me on the basis that I required proof of receipt of blood transfusions. I returned to Dr **GRO-B** requesting assistance in attaining my medical records.

34. We were informed that Eastbourne Hospital did not have any records. Dr **GRO-B** was diligent and looked through all my records and finally found the notes from when I had my two sons. It showed clearly that I had received transfusions on both occasions. Dr **GRO-B** printed off copies which were forwarded to Skipton. On 22 April 2015, my application was accepted and I received a stage 1 payment of £20,000.

35. I was not initially aware that I would be eligible for stage 2 payment if I were to develop cirrhosis. As I went on to develop cirrhosis, I was informed that I was eligible for an additional payment. I can't remember how we obtained the new forms but we completed the application, following which I received £50,000.

36. Apart from the requirement of proof, Skipton have been very kind and helpful. I have had no trouble with them at all. I must admit, I did panic as I didn't know how I was going to prove that I had received blood. That did set us back a bit. Thankfully the evidence was found. EIBSS have been very good too. I now get a monthly amount which has increased each year.

37. When I received the £20,000 and the £50,000, I distributed the payments between my husband and sons. They have all been through a lot, and GRO-B in particular, who has accompanied me to all my appointments and witnessed my physical and psychological anguish. I thought that they deserved some compensation. It made me feel better to share the money after what I put them through, although of course it wasn't my fault that I received contaminated blood.

38. I wouldn't dream of expecting or asking for more money. I feel that Skipton and EIBSS have been very generous. I remember when I first spoke to an administrator from the Skipton Fund. I explained my circumstances and he was very nice. He said he had Hepatitis C and HIV. I assumed that he would have received compensation. However, he wasn't eligible as he had contracted the viruses through other means. I was thankful that I had only got HCV and it was through contaminated blood rather than any other sources.

#### **Section 8. Other Issues**

39. It is very sad that a lot of people have died as a result of receiving contaminated blood. I am very grateful for everything that has been done for me. I feel very fortunate that I have got this far when a lot of people have died. This makes me feel that I don't have the right to complain. I don't want to be selfish and act as if I am the only one who has suffered as a result of contaminated blood. I still feel very fortunate to have survived. Nevertheless, I have endured a lot and my prognosis in the future remains unknown.

# ANONYMOUS

## Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed

GRO-B

Dated

16/11/21